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Navigating Challenges to Facilitate Success for College Students with Autism

Bradley E. Cox[a], Jeffrey Edelstein[b], Bailey Brogdon[c], and Amanda Roy[d]

[a]Educational Leadership and Policy Studies, Florida State University, Tallahassee, Florida, USA; [b]Educational Policy, Research, and Administration, University of Massachusetts Amherst, Amherst, Massachusetts, USA; [c]School of Pharmacy, University of South Florida, Tampa, Florida, USA; [d]Residential Life, University of Washington, Seattle, Washington, USA

ABSTRACT

Roughly 1 in 59 children in the United States is diagnosed with an autism spectrum disorder (ASD), a rate that has more than doubled during the last 10 years. As students with autism increasingly pursue higher education, college educators must understand these students' experiences and actively address issues that affect their college outcomes. This paper draws from interviews with autistic students who have had widely varying experiences and outcomes in higher education. Using an iterative analytic strategy that combined elements of grounded theory, multiple case study, and constant comparative approaches, researchers developed a series of propositions that were subsequently deconstructed and reconstituted as a conceptual model. The resultant conceptual model not only provides a descriptive portrait of how these students experienced interactions with their postsecondary institutions but also outlines specific ways in which tensions between the student and institution manifest as acute problems that students were often able to recognize, sometimes able to reframe, and occasionally able to resolve. The "3R" model can be used to help students and their institutions anticipate, address, and overcome challenges in ways that improve college experiences and outcomes for students on the autism spectrum.

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With recent increases in public awareness, early interventions, and K-12 educational support, an increasing number of students with autism spectrum disorder (ASD)[1] are ready and able to succeed in higher education (Chiang et al., 2012). Yet, national data indicate that only 34.7% of students with autism attend a 2- or 4-year college (Shattuck et al., 2012), with fewer than 39% of those completing their degrees (Newman et al., 2011). Improving these statistics will require college educators to understand these students' experiences and actively address issues that affect their college outcomes. Drawing from interviews with autistic adults who have attended college, this paper (1) describes these students' interactions with their postsecondary institutions; (2) outlines a process through which students and colleges can recognize, reframe, and resolve tensions arising from those interactions; and (3) offers suggestions for how to adjust institutional practice and

CONTACT Bradley E. Cox brad.cox@fsu.edu
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advance educational research in ways that improve college experiences and outcomes for students with autism.

Summary of relevant literature

Autism is a neurological variation characterized by qualitative differences in the development of cognitive, language, social, and/or motor skills. Autism occurs on a spectrum, so the characteristics of ASD appear differently in each person. These differences are often observed through challenges in social communication, forming relationships, and grasping abstract concepts. As a formal diagnostic label, ASD is defined as a neurodevelopmental disorder characterized by "persistent deficits in social communication and social interaction across multiple contexts" and "restricted, repetitive patterns of behavior, interests, or activities" (American Psychiatric Association, 2013).

The literature on college students with autism, and the institutional initiatives designed to support them, is remarkably thin. A review by Peña (2014) revealed the top four journals in the field of higher education had published, collectively from 1990–2010, barely one article per year focused on students with *any* disability; the first mention of autism in any of those four journals did not occur until 2017 (Cox et al., 2017). The broader body of literature—including publications in fields like psychology, special education, and medicine—yields three overarching conclusions.

First, college outcomes for students with autism have much room for improvement. Nationally representative statistics indicate students with autism often delay college entry by several years (Shattuck et al., 2012) and disproportionately attend 2-year colleges (Wei et al., 2014). Overall, fewer than 39% of autistic students who enter college complete their degrees (Newman et al., 2011).

Second, the vast majority of the literature about college students with autism (see reviews by Gelbar et al., 2014; Nuske et al., 2019; Toor et al., 2016) explain these outcomes by describing the social, emotional, independent-living, self-advocacy, communication, and (to a lesser extent) academic challenges these students face in college (e.g., Adreon & Durocher, 2007; Anderson et al., 2017; Bolourian et al., 2018; Cai & Richdale, 2016; Freedman, 2010; Gobbo & Shmulsky, 2012, 2014; Jackson et al., 2018; McLeod et al., 2019; Sturm & Kasari, 2019; Van Hees et al., 2015). With few exceptions (e.g., MacLeod et al., 2018), studies that highlight positive postsecondary experiences for students with autism (e.g., Accardo et al., 2019; Anderson & Butt, 2017; Gurbuz et al., 2019; Lizotte, 2018; Shmulsky et al., 2017) typically focus on academic experiences and frequently present their discussions of success alongside equally extensive discussions of student challenges. These studies frequently argue that students can best overcome these challenges by recognizing how autism affects them and advocating for themselves to receive appropriate support (e.g., Roberts, 2010, Wehman et al.,

2014), while Ward and Webster (2018) specifically name problem-solving as "critical" to students' college success.

Third, there is little evidence about what postsecondary institutions can do to address these issues or facilitate success for college students with autism. Studies by Accardo et al. (2018) and Scheef et al. (2019) note that some students find value in academic accommodations like extended time on tests, but far more studies suggest these traditional disability accommodations may be inadequate for students with autism (e.g., Knott & Taylor, 2014; Roux et al., 2015; Sarrett, 2018; Van Hees et al., 2015). Students also report wanting, but not adequately receiving, individualized support for navigating interactions with their peers, instructors, and the physical environment (e.g., Anderson et al., 2017; Bolourian et al., 2018; Sarrett, 2018). When students describe things that help them succeed, they tend to mention specific individuals like family members, friends, or faculty/staff (Anderson et al., 2019; Anderson & Butt, 2017; Cox et al., 2017; LeGary, 2017); references to supportive institution-level environments, policies, or practices are comparatively infrequent.

Instead, many widely implemented institutional initiatives designed to facilitate student success may be counter-productive for students with autism. Guided by prominent student success models that emphasize student integration (Tinto, 1975), involvement (Astin, 1999), and engagement (Kuh et al., 2007), colleges and universities often encourage students to live on campus, join student organizations, and interact with faculty outside the classroom. Six of Kuh's (2008) ten high-impact practices make explicit reference to experiences that place students in unfamiliar environments (service learning, global learning/study abroad, internships), or require frequent interactions with faculty, staff, or student peers (first-year seminars, learning communities, collaborative assignments). Yet, it is precisely these types of activities autistic students report as particularly difficult for them, in part because universities offer little guidance for how to navigate these situations (e.g., Anderson & Butt, 2017; Cox et al., 2017; Hendricks & Wehman, 2009; Jackson et al., 2018; Sarrett, 2018).

Finally, much of the current literature relies heavily on data collected from people other than autistic college students—faculty (e.g., Gobbo & Shmulsky, 2014), postsecondary service providers (e.g., Barnhill, 2016), peers (e.g., Nevill & White, 2011), and/or parents (e.g., Taylor & Seltzer, 2011, 2012)—thereby minimizing the voices and subtly undermining the agency of students themselves. In this study, our findings emerge from the first-person narratives of autistic individuals' own descriptions of their college experiences.

Framing the study and author positionality

Scholars have approached the study of disability through several distinct paradigmatic lenses (Brown et al., 2019; Kimball et al., 2016). Language from the Americans with Disabilities Act (ADA) reflects the *medical* model

by situating disability within an individual who has "a physical or mental impairment that substantially limits one or more major life activities" (42U.S. Code §12102). This model dominates the fields of medicine and psychology, but also features prominently in the study of disability in higher education (Kimball et al., 2016). In contrast, the *social* model describes disability as occurring when environmental (e.g., physical, social, political) conditions disable individuals by creating barriers to access, opportunity, participation, and/or achievement. Other frameworks—including *minority group* models, *cultural disability* studies, and *DisCrit* (disability critical race theory)—reflect a social justice orientation, although these models are largely absent from the literature on college students with disabilities (Brown et al., 2019; Kimball et al., 2016).

A recently emerging perspective is the notion of *neurodiversity*. Neurodiversity characterizes autism (and other brain-based differences; Armstrong, 2010) as one permutation of the variability of human existence (Jaarsma & Welin, 2012; Kapp, 2020; Silberman, 2015; Singer, 1999). Although neurodiversity acknowledges the existence of an underlying medical/biological cause of autism, it rejects the pathologizing of autism. Instead, it argues that characteristics of autism could be viewed as strengths if they were not devalued within socially constructed environments (Armstrong, 2010). The neurodiversity movement has become a centerpiece of political and academic efforts to shift funding for autism research from basic research in search of a cure to more applied research designed to improve autistic individuals' quality of life. Nonetheless, even among advocates of neurodiversity, there are several ongoing debates about whether autism should be labeled a disability (e.g., Hussman, 2013), and whether the term neurodiversity (a) is applicable to *all* individuals on the autism spectrum, (b) reduces the complexity of autism too much, and/or (c) has become politically divisive (for a review, see Russell, 2020).

We approach this study through a lens largely consistent with Shakespeare's (2013) interpretation of *critical realism*. Brown et al. (2019) highlight critical realism as a promising model that has heretofore been overlooked in much of the literature on higher education and disability. This model accepts that "disabilities exist on molecular, biological, physiological, emotional, interactional, institutional, and cultural levels simultaneously, and all of these are equally real" (Brown et al., 2019, p. 26). It also highlights the importance of investigating each of these levels both independently and interactively. Critical realism is particularly appropriate for the study of autism in higher education because it encourages multi-discliplinary and multi-theoretical approaches, consistent with Friedensen and Kimball (2017) argument that the complexity of disability identity development among college students requires scholars to consider multiple models, theories, or frameworks simultaneously.

Our ability to examine students' experiences from multiple perspectives was influenced by the varying personal and professional positionalities of this paper's authors. The lead author is a faculty member in higher education with an autistic son. The second, third, and fourth authors were (respectively, at the time of data collection and analyses), an undergraduate music major with a brother on the autism spectrum, an undergraduate in a pre-pharmacy track, and a higher education master's degree student working in campus housing. Our varied disciplinary groundings and personal connections to autism led us to collectively …

(1) acknowledge that the characteristics of autism may manifest as personal strengths,
(2) accept that those characteristics might also include functional limitations,
(3) recognize that college structures, policies, practices, and norms can create unnecessary difficulties for autistic students, and
(4) believe that institutions of higher education have the responsibility to foster environmental conditions in which autistic students can thrive without the need to self-identify or seek formal accommodations.

Methods

Participants

We sought to interview individuals with formal diagnoses of ASD who were in college currently or previously had attended a postsecondary institution in pursuit of a certificate, associate's degree, or bachelor's degree. Participants were recruited through a state-funded organization which provides free support and resources to individuals with autism. This organization distributed flyers and sent e-mails to eligible individuals and mentioned the study when meeting with clients; confidentiality restrictions prevented the research team from any direct communication with potential participants until they contacted us. Of the 118 individuals identified by the organization as eligible for the study, eight responded and were subsequently enrolled in the study.

This study's participants, introduced in Table 1, had a wide range of postsecondary experiences. One student had completed two master's degrees (including one online) and was nearing dissertation stage on his PhD; two others had completed their bachelor's degrees. Four students were actively enrolled at a technical or community college, while another had recently stopped-out of community college. The study's participants ranged in age from 19 to over 50. Age of initial diagnosis varied widely, with one participant getting an autism diagnosis at three years old, while another was in his forties. The racial and gender composition of the sample, however, was far more homogenous. All participants presented as White/Caucasian, though an oversight in data collection did not explicitly ask participants to self-identify racially. Seven of the eight students

Table 1. Interview participants[a]

Participant	Age	Sex	Gender	Age at Diagnosis	Highest Degree Completed	Active/Pending Enrollment
Adam	30+	Male	Male	3	Master's Degree	Doctoral Program
Brian	50+	Male	Male	40s	High School	Technical School
Christopher	24	Male	Male	8 or 9	Bachelor's Degree	
Danielle[b]	20+	Male	Female	9	High School	Community College
Edmund	21	Male	Male	15 or 16	GED	Community College
Franklin	23	Male	Male		High School	Community College
Gregory	33	Male	Male	26	Bachelor's Degree	
Harper	19	Male	Male		GED	

Note. Table adapted from "College Experiences for Students With Autism Spectrum Disorder: Personal Identity, Public Disclosure, and Institutional Support," by B. E. Cox, et al., 2017, Journal of College Student Development, 58(1), p. 76 (https://doi.org/10.1353/csd.2017.0004). Copyright 2017 by the American College Personnel Association.

[a]All participants presented as White/Caucasian, though an oversight in data collection did not explicitly ask participants to self-identify racially.

[b]Danielle, born male, spoke of experiencing gender dysphoria and was seeking hormone treatments.

identified as male; one student (Danielle) was born male but spoke of experiencing gender dysphoria and was seeking hormone treatments.

Data collection

Semi-structured interviews, consistent with the guidelines provided by Fetterman (1998), were conducted in a location familiar to each of the participants. Before being prompted with questions, the participants reviewed an outline of the interview questions which served as a guide throughout the interview. The questions asked students about their backgrounds, college experiences, and subsequent outcomes. For example, participants were asked to explain their initial ideas about college, whether they disclosed their ASD diagnosis, and their development of academic, social, and independent-living skills; subsequent probing questions solicited additional details or specific examples of critical events. Students tended to give short, narrowly-tailored responses focused on concrete details even when asked to speak about personal interpretations of or feelings toward specific events, incidents, interactions, or communications. The interviewer often used multiple probing questions with slight tweaks in the framing or language to piece together a more comprehensive understanding of a student's experiences. Interviews ranged from 50 to 90 minutes, with breaks allowed when requested. Seven interviews were conducted one-on-one and video recorded. The eighth participant requested a classmate sit in on the interview and audio recording only. All the interviews were professionally transcribed with the audio/video recordings time-synched with the transcripts.

Analytic Approach

The analyses of these data occurred in three distinct phases, combining grounded theory, multiple case study, and constant comparative approaches (Charmaz, 2006; Corbin & Strauss, 2008; Creswell, 1998). During Phase 1, throughout the

data collection process, we took a constant comparative approach (Corbin & Strauss, 2008) whereby data collection and analyses were conducted iteratively, with concepts from previous interviews explicitly explored in subsequent interviews with other students. Phase 2 involved descriptive coding of interview transcripts. The Phase 2 coders had previously applied the same coding structure to transcripts from online discussion forums for individuals with autism, during which the coders underwent several rounds of coding the same data and subsequently meeting to reconcile any disagreements (Anderson et al., 2019). The coders also wrote reflective memos and created new codes in-vivo as they recognized patterns that did not fit into the a-priori coding structure.

Phase 3 involved a multi-step process. First, the third and fourth authors, neither of whom had been exposed previously to the interviews, independently reviewed the interviews, transcripts, and codes. Along the way, each generated two to four propositions, roughly analogous to the causal chains typical of grounded theory (Charmaz, 2006). Through a series of meetings with the full research team, these propositions were subsequently clarified, revised, and mapped onto representative quotations from the interviews. To protect against potential confirmation bias, each proposition was evaluated subsequently by a different researcher who returned to the original data explicitly in search of disconfirming or contradictory evidence.

During the team's final meeting, we attempted to refine, remove, or reconfirm each distinct proposition in light of both the supporting and contradicting evidence. While trying to do so, however, we came to realize the ideas described in the propositions were not mutually exclusive. Rather, they were overlapping, connected, and interdependent. Guided by this realization, we deconstructed them as distinct propositions and reconstructed them as a series of connected concepts highlighting the manner in which autistic students' college experiences and outcomes are shaped by the interaction between the students and their postsecondary institutions. We concluded our analyses by conducting a series of searches within the interview transcripts to determine how frequently certain keywords were used by the interviewer and/or student.

Limitations, credibility, and transferability

This study is subject to several limitations, the most prominent of which relate to the sample of participants. The sample includes eight current and former college students with formal ASD diagnoses, though two had not been diagnosed at the time of college entry. While the sample is relatively small, its size is consistent with other studies about autistic college students. None of the articles reviewed by Gelbar et al. (2014) included more than 12 participants, and seven of the 20 articles included just one participant. Likewise, half of the studies reviewed by Kuder and Accardo (2018) were based on a single student, with the largest qualitative sample including only three students.

There is considerable diversity among this study's participants with regard to age, institutions attended, and presentation of autism-related characteristics. In other ways, however, the sample is more homogenous than would be desired. Most of the students were male and all the students presented racially as White. Participants were also geographically clustered at the time of the interview (though several had previously lived and attended college in other states or countries), residing in one of ten contiguous counties where many of their postsecondary institutions were located. Moreover, by voluntarily registering with an ASD service organization and pursuing higher education, the participants demonstrated levels of self-awareness, help-seeking behavior, cognitive ability, and communication skills that, while possibly reflective of the 34.7% of autistic high school completers who subsequently pursue higher education (Shattuck, Narendorf, et al., 2012), is not representative of the entire autism spectrum.

Efforts to recruit a more diverse sample were blunted by our lack of direct communication with potential participants, a condition of our agreement with our university's ethical review board and the ASD service organization enacted to protect people's privacy. Nonetheless, the composition of our sample is somewhat reflective of race, gender, and location-related inequalities in access to diagnoses, education, and support services (e.g., Baio et al., 2018; Fombonne, 2009; Palmer et al., 2010; Pearson & Meadan, 2018; Shattuck, Narendorf, et al., 2012; Thomas et al., 2007; Travers & Krezmien, 2018; Travers, et al., 2012; Zuckerman et al., 2017). Collectively, these issues with the sample mean we can make no formal claims of generalizability. We suggest only that the findings presented in this paper can provide a reasonable starting point when considering the experiences of college students with autism in other contexts.

We enacted a number of safeguards to help protect against potential threats to credibility, ensure authenticity, and maximize transferability. For example, viewing synchronized videos and transcripts ensured descriptive accuracy of the transcripts. Doing so also provided a form of data triangulation that supports interpretive validity, as we were able to ensure codes generated from transcripts were consistent with the students' nonverbal cues. The use of multiple researchers coding data independently, but meeting periodically to ensure convergence, further contributed to descriptive and interpretive validity. In particular, the two researchers leading Phase 3 had a fresh perspective (having not previously worked together or seen the interview data), allowing them to independently develop their initial propositions. Subsequent inclusion of the Phase 1 and Phase 2 analysts in the final proposition reconciliation meetings also helped ensure the conclusions from Phase 3 were broadly consistent with observations made during the first two phases of analyses. Moreover, the explicit search for disconfirming evidence served to counter any unconscious tendency for the original proposition-generator to privilege supporting data and overlook contradictory evidence. The word-frequency queries within the interview transcripts supported authenticity by

ensuring our use of language was reflective of students' own voices. Finally, we solicited comments on this paper from a colleague who, in addition to being an autistic self-advocate, had recently conducted interviews with community college students with autism for an unrelated study. His feedback indicated that our framing of the findings was linguistically appropriate, consistent with data from his study, and potentially applicable beyond the specific context in which we collected data.

Findings

Navigating challenges to facilitate success

When recalling their journeys through higher education, students frequently described pivotal moments in their college experiences in terms of running into problems, having difficulty, and facing challenges. The students used this type of negative terminology in a variety of ways. Students often spoke matter-of-factly about specific college outcomes, particularly course completion and grades, without assigning a cause to those outcomes. When describing his most recent college experience, for example, Edmund stated simply "I had to pick my grades up this last semester, but, because I kind of failed some of the exams and things." At other times, students would see the problems as their own fault. Christopher spoke broadly of getting "frustrated with school and I'll just, I know I have problems but that's not good" while Franklin talked about a specific class where he "didn't do so hot on [the tests because] … I'm just not very good at them without notes." Students would elsewhere suggest their postsecondary institutions had created the problem. For example, Gregory said "the problem was they kept changing counselors on me" and Adam wished his instructors would have stopped "assuming that I was going to fail out or get a C or whatever."

Student references to such issues during their college experiences were pervasive. In fact, a query of the interview transcripts using the most liberal search parameters (i.e., including word synonyms in the broad context, as defined by NVivo) found 357 references to "fail," 123 references to "problem," and 109 references to "success" or "succeed." We subsequently explored word use more granularly by conducting a one-by-one review of each individual instance of "problem" and "success" to determine whether it was the interviewer or student who used the term. Of the 60 times the exact word "success(es)" shows up in the verbatim transcripts, 45 (75%) were uttered by the interviewer and 15 (25%) were said by the students. Of the 88 times the exact word "problem(s)" appears, only 10 (11%) came from the interviewer while 78 (89%) were said by the students. These data confirm that, despite repeated efforts by the interviewer to frame the conversations in terms of college success, the students themselves described their efforts toward college success in terms of the obstacles they encountered along the way.

The tension between our desire to identify positive experiences that facilitate postsecondary success and students' tendency to describe their experiences in negative terms was salient throughout our analyses. The results of our iterative proposition refinement process exemplify this tension. Our four penultimate propositions were:

(1) Students diagnosed with autism benefit from a wise, supportive, and understanding mentor, who, by helping the student effectively navigate challenges encountered in college, helps the student build the confidence to address future challenges independently.
(2) Identity salience of students' ASD diagnoses impacts self-advocacy and meaning-making when faced with challenges within a university setting.
(3) Students diagnosed with autism spectrum disorders are more willing to focus on the bureaucratic procedures and academics of higher education, rather than social aspects, due to fear.
(4) The strength of institutional support systems (e.g., advising, housing, tutoring) impacts the ability of students with autism to navigate the higher education landscape, find a sense of belonging, and successfully graduate from the institution.

During the meeting in which we had planned to finalize the specific wording of each proposition we realized that, although each of these propositions had been generated and evaluated independently, the underlying ideas outlined in the propositions were interconnected. Two prominent threads weave through the propositions. First, students' experiences are shaped by interactions between the individual student (e.g., identity salience, sense of belonging) and their institutional environment (e.g., people, services). Second, these students must navigate a range of challenges that emerge from their interactions with that environment. In light of these observations, we deconstructed each of the propositions and sought to reconceptualize the relationships between their component parts.

Because the current literature is already replete with descriptions of various challenges autistic students face while in college, we instead reconstructed the pieces of our propositions in a way that can help individual students and postsecondary institutions facilitate these students' success. Nonetheless, we honor the perspectives of the students while minimizing the superimposition of our own by presenting our findings as a process through which problems that might otherwise have interfered with students' opportunities for college success could be recognized, reframed, and resolved. Neither the term "problem," the propositions, the presentation of findings below, nor the discussion that follows assign exclusive blame for causing, nor exclusive responsibility for resolving, the problems students encountered while pursuing higher education.

Recognize: autism-related characteristics and institutional norms

> *"It's not fair to us autistic people. It's not designed for us autistic people"* — Brian

Although the manifestation of autism was different for each student, most expressed awareness of their specific autism-related characteristics and the role those characteristics played in shaping their college experiences. Edmund explained,

> My symptoms are still underlying and they're still there but I learned to work with it . . .. I'm deathly afraid of heights. I cannot make it into certain buildings . . . I think I still have problems keeping my focus, it's still there but I try to control it. I'm trying to get over the shyness . . . I do have problems, I do get confused every once in a while with instructions and where to go on campus and what to do.

Students described first encountering problems in college when their autism-related characteristics clashed with their institutions' implicit norms —particularly those related to instructional practices and professorial support—that neither appeared to consider nor proactively accommodate the distinctive characteristics of students with autism. For example, Brian suggested his struggles with coursework were due to the mismatch between how his brain worked and how material was presented in class. Brian said about students with autism, "We're linear learners, linear people. We're literal people." He called himself "a linear learner. I mean, I'm autistic. And if it's not linear I can't learn it. That's a problem, that's a major problem." He summarized by saying "It's not fair to us autistic people. It's not designed for us autistic people."

Large lecture classes, which students said were common at their 4-year universities, were singled out as particularly ineffective. Gregory suggested that professors in these classes would "come in [and] just like go straight to the board and as soon as they were done with the class they would drop the chalk and leave." In contrast, students who attended community college valued the smaller classes. Christopher noted that "the largest class I ever took there was maybe 20–25 students" while Gregory was thankful "there weren't 300 of us crammed into a lecture hall."

However, it was during the in-class discussions and group assignments commonly required in smaller courses that students' discomfort with social communication and peer interactions was especially salient. Edmund lamented,

> everybody else had been learning [social skills] naturally and with ease. But it had been very difficult [for me], I have never been able to grasp. And the thing is they don't teach you that kind of stuff in school.

Without a natural inclination to recognize or use what Gregory called "proper social skills," he found it "hard to say anything relative or relevant" in groups and was reluctant to approach peers for fear of saying something "silly" or "stupid."

As a result, Gregory "was kind of the guy who did what he was told . . . I was kind of just the guy in the background that kind of did the small stuff."

Edmund and Adam took a different approach to working with peers. Both had learned early in life that success in the educational system, the workforce, and society as a whole would require them to adhere to several implicit social conventions. Therefore, they learned how to govern certain behaviors in public, which allowed them to, as Adam put it, "fake out" his peers and instructors. Edmund explained,

> I've had to, like, had to control some of the ticks, banging my head against the floor and the wall and flapping my arms and all of that stuff. Uh, I mean I still do that stuff I just try not to do it in public. I do it when I get home.

But such behavioral control wasn't easy, and when Adam got "stressed or sleep deprived, my Asperger's gets a lot worse" and started to affect his interactions with peers.

In part because of the stress caused by unstructured interpersonal interactions, students were often reluctant to seek personalized support from instructors. Although Brian needed "someone to work with me more" he felt the professor "doesn't have time, she doesn't have the time to help me, not with all these other students." When asked whether he engaged his teachers about the role autism played in his academic experiences, Franklin stated simply "no." Christopher explained that "It never really came up with my professors what the nature of my disability was . . . Just for the sake of simplicity I just kept mum about the nature." Likewise, Evan said he had "not told any of my professors" in part because "I just don't see a reason for bringing it up."

When students did seek faculty support to address any issues affecting their classroom experiences, the standard responses from their professors rarely improved the situation. Christopher and Brian's instructors employed a common technique: referring the students to someone else. When Christopher approached an instructor for help in a first-year class, he was told his advisor "should've known better" than to put him in that class. Brian recounted that professors often said, "talk to your student advisor." For Adam, Christopher, Edmund, Danielle, and Franklin, efforts to address academic concerns instead required conversations with their schools' Disability Service Office (DSO).

Reframe: individual identity and formal accommodations

> "I don't like being labeled. I'm fine to say, to call myself autistic . . . but I don't like it when other people label me and make assumptions about me." — Adam

In part because students were able to receive immediate feedback and had clear indicators of their relative success with coursework, the students' first

recognition of problems in college typically related to academic issues. For most of the students, initial efforts to resolve these academic issues involved working with a campus Disability Service Office. Indeed, formal accommodations provided by a campus DSO were the most frequent answer given when students were asked how their institutions might have facilitated or inhibited their postsecondary success. Accommodations related to test taking (i.e., extended time or distraction-free environment) were mentioned by Adam, Christopher, Edmund, and Franklin. Students also referenced receiving notes from classmates, while Danielle sought permission to use a laptop to take notes in classes where an instructor might have banned technology otherwise.

Accessing such accommodations was not a simple matter. To receive accommodations, students said they needed to have a formal diagnosis (which didn't occur until after college started for Brian and Gregory) and provide documentation supporting the diagnosis (which had been completed 10 or more years ago for Adam, Christopher, and Danielle). Students expressed frustration with these requirements, with Danielle specifically noting that, because she had difficulty securing the necessary documentation when she requested formal accommodations at her previous community college, she planned to "get a long file so it doesn't seem like I'm just coming up with [it] suddenly."

The willingness to request disability accommodations, as well as the timing of such requests, was influenced by the manner in which students made sense of their autism diagnosis. All the participants in the study explicitly acknowledged to the interviewer that they were on the autism spectrum and had at least a basic understanding of autism. Most also demonstrated self-awareness about how the condition affects them. For example, Adam acknowledged that he does not have the "inborn ability that really organized people have to create structure" but explained that "Asperger's people need" structure. Brian concurred, noting that "for an autistic person it was pretty cool" to attend a rigidly structured and routinized military academy. Brian also apologized because "I can't look at you in the face all the time. That's the Asperger thing."

However, students varied in their acceptance of autism as a part of their personal identity. Brian, for example, labeled himself "a living, breathing Forrest Gump." In contrast, Gregory and Adam tended to resist stereotypical labels, instead employing more general terms when describing facets of autism. Adam explained "I don't like being labeled. I'm fine to say, to call myself autistic or you know Asperger's or bipolar but I don't like it when other people label me and make assumptions about me." Edmund, likewise, seemed to have accepted autism as one part, but not all, of his personal identity, noting "I'm comfortable in my own skin." Though he appeared self-accepting and did not consider autism as a highly salient part of his identity, Edmund believed it was "probably just some of the symptoms of my autism" that caused him difficulty at his community college. The students' self-awareness, self-acceptance, and self-advocacy came to the

forefront if/when problems initially thought to be academic in nature needed to be reframed after initial efforts to address them were not entirely effective.

Christopher's experience is exemplary of how students could reframe what had originally been believed to be an academic issue best resolved through coordination with the Disability Service Office. Having struggled during his high school calculus class, Christopher arranged a meeting with DSO staff and "some of the professors regarding the levels of calculus I'd have to take" in advance of a campus tour at his first-choice college. While there, however, he "had a bit of a panic attack." That discussion with campus personnel prompted Christopher to realize his difficulties were not only math-related. He explained afterward, "I honestly don't think I can do this. As much as I would love to be able to go here and study this, realistically I don't." Christopher also realized that, without his parents there with him, "I'm going to get lost." Thus, efforts to solve what Christopher had originally identified as a simple problem with his academic course requirements instead prompted Christopher to redefine the problem as a more complex mix of issues related to his academic preparation, independent living needs, and emotional readiness. Describing how he was able to reframe his academic difficulties to promote future success, Christopher explained, "I think a lot of that just comes from, just, I think the right word is introspection. Just spending time thinking about what your disability is, what's holding you back."

Edmund likewise described a situation where he had to reframe his thinking about academic difficulties early in his college career. Although he initially downplayed his role in earning poor grades in multiple courses, Edmund later realized "that was on me and that was my problem and now I just need to try and improve next semester." Upon reflection, he linked his acute academic problem to a larger issue related to his personal sense of identity, stating

> I feel like I'm getting into the responsibility [for himself]. … wow, this is what life's all about, huh, keeping on track and not neglecting your friends or your work ethic or your study habits. And like respecting yourself to some extent.

Christopher also spoke about how his evolving sense of self shaped his perception of the challenges he encountered in college:

> The 1st thing you need to know with any disability, the first thing you gotta do is you gotta get yourself in the right mindset. Another one of those phrases I've coined is that I am not disabled, I am differently abled. That's the first thing. You've gotta get yourself into a mindset where this is not something that's going to hold me back for the rest of my life.

Both Christopher and Edmund described the importance of taking personal responsibility and having a sense of self that was both realistic and empowering. Students who did so were proactive in efforts to shape their own college experiences.

Resolve: personal connections and personalized adaptations

> "Maybe you can overcome it with just you by yourself but, like I said, the odds are slim. You really need to have a support structure of some kind to help you." — Christopher

Even students who had a strong sense of personal agency spoke of needing external support to address specific challenges they encountered in college. As Christopher noted, "Maybe you can overcome it with just you by yourself but, like I said, the odds are slim. You really need to have a support structure of some kind to help you." He explained,

> "Your parents have to be on board. They have to be willing to help fight for you, because I know there are some families out there who are of the mind, as long as we don't acknowledge that there's anything wrong with you nothing's wrong with you. They just ignore the problem. And as a result you don't get the help you need. And you suffer for it."

For Adam, Christopher, and Edmund, family formed the foundation of that support structure. Students also received support from other sources. Edmund said he had received "a lot of support from friends and family, counselors, like people who were there to support me, the connections." Franklin's connections came through "support providers" like his behavioral therapist and "VR [Vocational Rehabilitation] counselor." In addition to occasional meetings in clinical settings, one such professional sometimes even "goes in my class basically … " and "observes" the class and subsequently "just talk[s] about what happened in class" with Franklin.

College offices and personnel were also mentioned as sources of support. One institution had a highly publicized area located in a central academic building that had numerous on-demand tutors. Christopher, Edmund, and Franklin praised the service and used it often. Gregory and David also spoke highly of some "passionate" and "supportive" teachers at their community college. Students who felt most positive about their efforts to resolve any issues spoke of having an institutional agent whose personalized interactions supported the student's pursuit of holistic well-being. Students who made strong connections with a specific employee (typically an instructor or advisor) were often recipients of personalized adaptations — instances in which institutional resources, accommodations, or policies were adapted to meet unique student needs.

Adam reflected on his experiences with a specific advisor who was "trained to listen" instead of only listing academic requirements. He went to that same advisor "for the rest of my time [at that college]" after the advisor compassionately listened to him after returning to class following a hospital stay. Likewise, Edmund highlighted the efforts of a particular English professor who "walked me through … tutored me" and another "very accommodating" instructor who "let me come to his office to finish my homework when I was running low on time to finish."

However, these instances of personalized adaptation were neither typical of the institutions nor indicative of larger systems of support for students with autism. On only two occasions did an interviewed student describe personalized adaptations that were enacted through coordinated institutional efforts. In the first case, through a series of discussions with administrators and instructors, Brian was allowed to conditionally re-enroll in a local technical college the semester after being dismissed because of a conduct complaint. In the second, Christopher was allowed to retake a course,

> for a forgiveness grade. This time we got — we actually talked to both the staff at the [tutoring center] and the staff at the Disability Service Office. And the two worked together to get me set up with a, uh, a specialized tutor.

By leveraging their connections to personal support systems, and by embracing whatever personalized adaptations students received from their postsecondary institutions, some students were able to resolve specific problems encountered in college. Conversely, the lack of such personalized adaptation left other students vulnerable to difficulties. David experienced a significant illness and began missing class and failing exams. His professors neither noticed nor reached out; if they had, David said he "would have realized I needed to . . . medically withdraw . . . but that didn't happen," and the resulting poor performance caused complications as he pursued his subsequent coursework.

Adam also recognized the importance of reshaping institution-wide policy, practice, and culture. Specifically, Adam suggested the need for better faculty training, incorporation of disability policy discussions into classroom lectures, increased presentations by advisors or DSO personnel, and even a revamping of the traditional orientation session so students "don't get this massive information all at once and then forget it all and then they don't go to use the resources when they need them." With these changes, institutions could implement

> some way of structuring the college experience so that people like, especially, you know, autistic people or Asperger's people who need more support or could use more support, to somehow remind them in a formal way that these services exist without, you know, making a big fuss about it.

Linking the intersections: the recognize, reframe, and resolve (3R) model

Each of the three previous sections highlights a specific point of intersection between the individual student and their postsecondary institution. When put together visually (see Figure 1), these points of intersection yield a pathway through which problems affecting students' postsecondary success can be recognized, reframed, and resolved. The model highlights how subtle tensions between the individual and the institution can become tangible problems during specific instances of intersection between the student and the school.

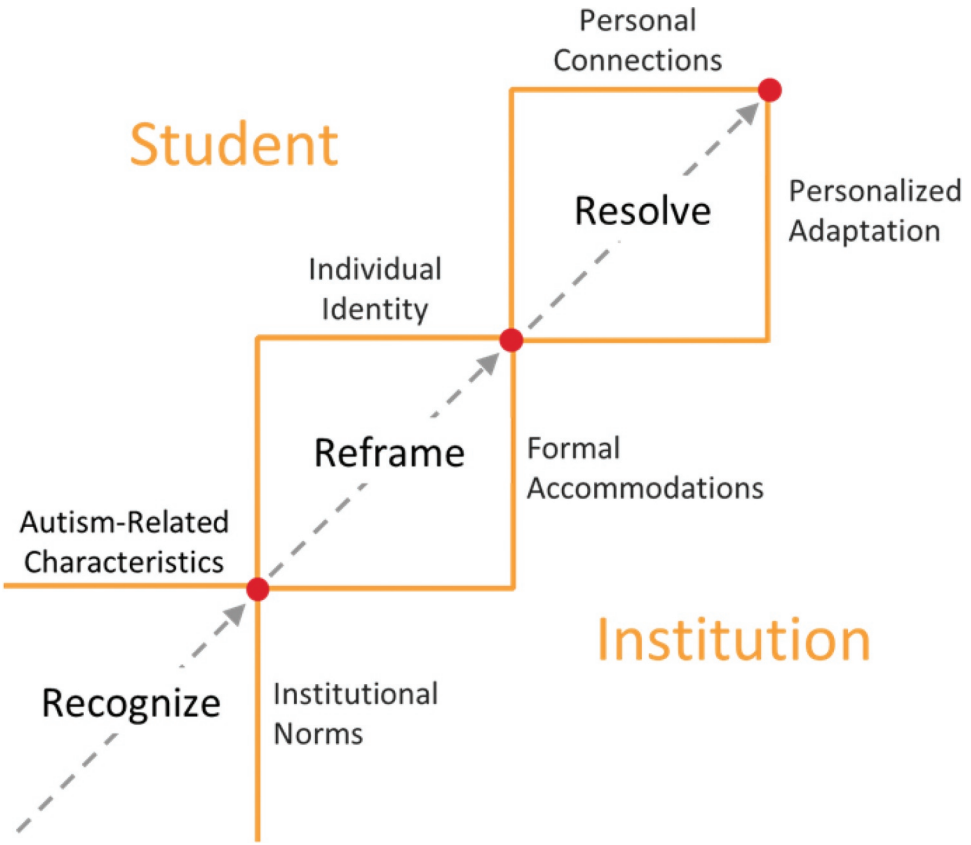

Figure 1. Recognizing, Reframing, and Resolving Problems Affecting College Students with Autism.

The model also reinforces the notion that both students *and* institutions have roles to play in recognizing, reframing, and resolving those problems in ways that facilitate college success for students with autism.

Discussion

The autistic students in this study made frequent mention of wide-ranging issues, problems, or challenges that punctuated their college experiences. Although the students' language indicates some degree of internalized ableism (Campbell, 2008; Hutcheon & Wolbring, 2012; Kattari et al., 2018), the students also perceived these challenges to result as much from limitations of their postsecondary institutions as from their own autism-related characteristics. Our model reflects this by outlining specific ways in which tensions between the student and institution, though likely always present even if unrecognized, manifest in acute problems that were often recognized, sometimes reframed, and occasionally resolved.

When students took efforts to resolve these issues, they employed a repertoire of approaches that is largely consistent with the most common suggestions offered by scholars who have thus far populated the literature on college students with autism (e.g., Lizotte, 2018; Roberts, 2010; Roux et al., 2015; Van Hees et al., 2015). These students affirmed the importance of disclosing their status to the DSO, acquiring appropriate accommodations, advocating for themselves, and pursing opportunities for skill development. Edmond and Gregory exemplify how such student-initiated efforts can contribute to postsecondary success. In the remainder of this discussion section, however, we challenge the prevailing norm that places the burden of change on autistic students themselves by focusing on ways higher education researchers, administrators, and practitioners can reevaluate and revise their own policies, practices, and norms to improve college experiences and outcomes for students with autism. Finally, to encourage scholarly dialogue and promote future research on this topic, we conclude the paper with a transparent discussion of the personal, methodological, and ethical tensions we have navigated throughout this project.

Improving support services for autistic college students

Our study's findings highlight the extent to which institutions of higher education have yet to effectively engage with autistic college students while creating an environment that places considerable burdens on students to seek out personal adaptations that will support their college success. As in Sarrett's (2018) study, the faculty members described in this study were less than accommodating, often blaming someone else (e.g., the advisor) or passing off the student to another office (e.g., the Disability Service Office). Faculty members' (and, we suspect, administrators') discomfort in these situations may relate to concerns about student privacy and the legal complexities surrounding FERPA and HIPAA laws (Bower & Schwartz, 2010), which can cause institutions to compartmentalize data and discussions about students with disabilities' (Rooker, 2004). Yet, failure to engage in these discussions limits the ability of colleges and universities to adapt to meet these students' needs and perpetuates the expectation that the students must instead adapt to the institution.

Even the Disability Service Offices explicitly charged with supporting college students with autism and other disabilities can place considerable barriers between students and the accommodations they should be afforded. Students typically had to provide external medical/psychological documentation indicating they have a disability warranting accommodations. Indeed, Danielle spoke of the need to "get a long file" after she was denied such accommodations at her original institution. Developing such a long file with formal assessments indicating an autism diagnosis would prove difficult for the four students whose original diagnosis was made more than a decade before starting college; it

would be impossible for the two interviewed students who did not have their diagnosis when they first enrolled. The requirement for external validation of students' disability status via formal documentation remains widespread (Lindstrom et al., 2013; Madaus et al., 2010) despite guidance from the Association on Higher Education And Disabilities (AHEAD, 2012) which states that "postsecondary institutions cannot create documentation processes that are burdensome" (p. 4), and that formal assessments generated by third parties are to be considered only as "tertiary" (p. 2) documentation of eligibility. Decreasing the reliance on external documentation to establish student eligibility would decrease the burden placed upon autistic students and increase the timeliness with which DSOs could provide appropriate accommodations.

More broadly, colleges and universities must reconsider the types of support made available to autistic students. Consistent with other research (Accardo et al., 2018; Brown & Coomes, 2015; Newman et al., 2011; Roux et al., 2015; Sarrett, 2018), most of the students in this study spoke of receiving traditional academic accommodations (e.g., extended time on tests, quiet location for test taking). Yet, recent scholarship argues that autistic students may benefit more from non-traditional supports like customized transition programs, sensory-friendly spaces, social support groups, and faculty or peer mentors (Accardo et al., 2018; Brown & Coomes, 2015; Knott & Taylor, 2014; Roux et al., 2015; Sarrett, 2018).

Seventy-four colleges in the U.S. have begun to explore these alternate approaches by initiating comprehensive autism-specific college support programs (McDermott & Nachman, 2020). Having doubled in number over the last 5 years (Barnhill, 2016), the programs vary dramatically both in terms of their structures (e.g., program size, staffing, administrative oversight) and the services they provide (e.g., peer mentors, social skills training, tutoring). However, these autism-specific college support programs typically have fees averaging 6,525 USD annually (Barnhill, 2016) that must be paid in addition to regular tuition. Moreover, few of these programs have been externally evaluated, with recent reviews uncovering only seven (Paskins et al., 2018) or eight (Kuder & Accardo, 2018) empirical studies evaluating postsecondary interventions. Evidence regarding the effectiveness of these alternate support services—whether delivered independently or as part of a comprehensive program—remains limited and inconsistent.

Advancing research on college students with autism

Improving experiences and outcomes for college students with autism will require postsecondary institutions to implement effective, affordable, and equitable support services uniquely tailored to this population. Before that can happen, however, scholars need to dedicate more scholarly attention to the topic in ways that overcome persistent limitations in the current body of

literature. In this section, we document several of the tensions we have felt throughout this study in hopes it will help other scholars anticipate and navigate challenges likely to arise when conducting similar work.

Recruitment

It can be incredibly difficult to identify, recruit, and enroll students with autism as study participants. Our sample, like most studies on this topic, was relatively small. Although it might have been easier to recruit students through our campus's Disability Service Office, we chose not to do so because fewer than one third of students with disabilities register with such an office in college (Newman et al., 2011). By going through a community organization, we were able to (potentially) reach individuals who had a wider range of postsecondary experiences (e.g., institution type, current enrollment status, credentials earned). To do so we ceded control of the recruitment process to that external organization and, thus, were unable to make on-the-fly adjustments that might have increased the diversity of our sample. One alternate approach would be to screen a cross-section of college students using a short quantitative instrument (e.g., Allison et al., 2012) to identify students who report having several autism-related characteristics, regardless of formal diagnosis. Another alternative would be to work with local K-12 systems to recruit students with autism-specific IEPs who could then be tracked into higher education, even if they do not register with a DSO in college.

Interview setting and structure

Although many of the general principles for effective interviewing hold true for interviews with autistic students, implementation of those principles required several adaptations and much flexibility by the interviewer. We adapted the environment to maximize students' comfort by turning off the camera at times, allowing a peer to accompany the autistic student, and providing multiple breaks even in the shortest interviews. We made sure our interview protocol was structured linearly/chronologically and provided students a printed interview guide highlighting the key questions they would be asked to answer. These two things were particularly helpful as they allowed students to predict what questions would be coming next and served as an anchor to refocus the conversation when it strayed from its overarching purpose.

Interview practices

Students with autism have distinctive social communication practices that, while anticipated by the interviewer, were nonetheless challenging to navigate during the interview itself. The interviews tended to be fragmented rather than flowing. Students interpreted the phrasing of questions quite literally and generally provided short, narrowly constrained responses that were presented as objective descriptions of what they considered facts. If the student managed

to turn the discussion toward their preferred topic, it could prove difficult to return the conversation to their college experience. For example, more than 20 minutes of Franklin's interview was consumed by him talking about and playing audio clips from his favorite sports radio show, while questions about his college experience rarely got a response longer than four words. As a result, the interviewer frequently needed to redirect students toward the printed interview guide and/or repeatedly tweak the phrasing of a single question through multiple probes.

Analyses

Conducting the analyses of the resulting transcripts also presented two unique challenges. First, students' responses were often presented as though they were objectively true and independent of the individual student. Students infrequently spoke about their personal feelings or discussed potential alternate interpretations of, or perspectives on, specific events. Accordingly, our initial codes were heavy with descriptive details about specific events, but comparatively light on students' sense-making processes. Second, the fragmented conversations, literal interpretation of questions, and short responses meant we often had to piece together student stories by connecting snippets of comments provided in response to different questions.

Interpretation and presentation of findings

The most persistent tension we have felt throughout this project has been between (a) the researchers' desires to advance a narrative highlighting the positive experiences of college students with autism; (b) the students' description of their experiences in far more negative terms; and (c) the effort to support student agency by honoring their perceptions and amplifying their voices. Whether we got that balance right surely is up for debate, but we have actively engaged this tension throughout the research process and have been transparent throughout this manuscript about our efforts to do so. We hope other scholars will do the same.

Conclusion

In 2002, 1 in 150 children was diagnosed with autism; today, the number is 1 in 59 (Baio et al., 2018). In between, improvements to the diagnosis process, early interventions, and K-12 educational systems have dramatically increased the number of autistic students who complete high school ready and able to pursue higher education. Yet, the students in our study repeatedly spoke of personal challenges and institutional obstacles that would manifest as acute problems disrupting their journeys toward postsecondary success. Moreover, the field of higher education—including researchers, instructors, staff, and administrators—has been slow to recognize, understand, and respond to the recent influx of

college students with autism. The Recognize, Reframe, and Resolve (3 R) model presented in this paper can serve as an initial framework around which scholars of higher education can accelerate research about college students with autism, especially through studies that amplify the voices of autistic students themselves. Equally important, the model can be used by both individual students and postsecondary institutions to anticipate potential problems, establish effective supports, and develop personally adaptive environments that facilitate success for the large and growing number of college students with autism.

Note

1. There is considerable disagreement about language associated with autism. Some advocates prefer "identity-first" language (e.g., autistic student), while others promote "person-first" language (e.g., individual with autism). Students in this study used a variety of terms to describe themselves. Therefore, we keep the language used by students in all quotes, and otherwise use both person-first and identity-first language interchangeably. Likewise, we use the terms autism, autism spectrum disorder, and ASD interchangeably.

Disclosure statement

No potential conflict of interest was reported by the authors.

ORCID

Bradley E. Cox http://orcid.org/0000-0001-6665-3651

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